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Autism and family functioning: The role of parental coping

Liliana Vargas

AUTISM AND FAMILY FUNCTIONING:

THE ROLE OF PARENTAL COPING

A Thesis

Presented to the

Faculty of

California State University,

San Bernardino

In Partial Fulfillment

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Master of Science

in

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ABSTRACT

The present study employed a family systems approach to investigate the effects of level of autism severity on family functioning as mediated by parental coping. Participants were mothers' of children with autism who were volunteers in an ongoing research program conducted within a university-based treatment center. Gilliam Autism Rating Scale - Second Edition (GARS-2) scores were available for all of the children and, as part of the broader program, parents completed the Coping Scale for Adults (which assesses a range of coping styles) and the Family Environment Scale (which provides positive and negative indicators of family functioning). It was hypothesized that nonproductive coping would mediate the relationship between level of autism severity and family conflict and cohesion. Data analyses indicated that nonproductive coping significantly mediated the relationship between level of autism severity and family cohesion and conflict. Results also suggested that level of autism severity was negatively related to family conflict. Furthermore, results indicated that as level of autism severity increased, the use of nonproductive coping strategies increased as well. The present study further examined the use of specific coping styles on family

cohesion and conflict. Evaluation of these findings suggest that parents who have a child diagnosed with severe autism may be employing maladaptive coping strategies, such as wishful thinking, blaming one self, or avoiding the situation. Implications for intervention approaches for individuals working with families of children with autism are suggested.

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CHAPTER ONE

INTRODUCTION

Raising a child with a disability can have an immense impact on the family. The experiences and stresses that are encountered by the presence of a disability may have a debilitating affect on the family, placing an excruciating amount of hardship on parents. Research has consistently shown that parents of children with developmental disabilities experience a greater degree of stress than parents of typically developing children (Baker, Blacher, Crnic, & Edelbrock, 2002; Baxter, Cummins, & Polack, 1995; Button, Pianta, & Marvin, 2001; Hadadian, 1994; Innocenti, Huh, & Boyce, 1992; Margalit & Ankonina, 1991). However, there is a growing body of literature suggesting that having a family member with a disability may not necessarily produce a negative impact on the family (Dyson, 1991, 1997; Mahoney, O'Sullivan, & Robinson, 1992; Perry, Harris, & Minnes, 2005; Taanila, Jarvelin, & Kokkonen, 1999; Wilgosh, & Scorgie, 2000). In fact, Taanila and colleagues found that the presence of a disability contributed to a positive quality of life for family members and greater family cohesion. Dyson (1997) found that although both mothers and fathers of children

with disabilities experienced a greater degree of stress than mothers and fathers of typically developing children there were no differences between the two groups in social support or family functioning. Thus, the presence of a disability within a family does not necessarily indicate that the family's ability to function will be impaired or that the stress experienced by parents will negatively impact the family.

Family adaptation appears to be a key factor in determining how the family will be affected by the presence of a disability. McCubbin and Patterson (1983) developed a process model known as the Family Adjustment and Adaptation (FAAR) model, which describes the phases of adjustment and adaptation of a family when encountered by a stressful event. According to the authors, families go through two distinct phases: adjustment and adaptation. In the initial phase, attempts of adjustment to a family stressor can be characterized by minimal change within the family system; families are likely to maintain already established patterns. McCubbin and Patterson refer to this as "family resistance to change." The coping strategies of avoidance, elimination, and assimilation determine the extent to which families are adjusting, which is measured along a continuum from bonadaptation to maladaptation.

Avoidance occurs when at least one member of the family denies the stressor. Elimination deals with a family's effort to relieve the demands associated by the stressor, and assimilation occurs when the family accepts the demands of the stressor.

When a family is unable to meet the demands placed by a stressor an imbalance known as a "family crisis" occurs within the family system. A family stressor becomes a family crisis when the family is continuously moving toward the maladjustment end of the continuum. This marks the beginning of the adaptation phase. In the adaptation phase the goal is to restore stability through structural change within the family system. Restructuring and consolidation are the two levels that comprise the adaptation phase. At the restructuring level a shared definition of the problem must be derived within the family. McCubbin and Patterson state that families who are able to restructure their family system are said to be using the "adaptive coping strategy of system maintenance," which includes the use of resources, problem solving and communication skills, and positive appraisals of the situation. These coping strategies are designed to 1) keep the family functioning as a unit, 2) maintain the esteem of members, and 3) maintain the family morale.

At the second level of the adaptation phase, consolidation, families continue to make changes to restore stability. The goal here is for the family to function as a coherent unit. In this phase the entire family unit works together to implement agreed upon changes. Successful consolidation occurs through the adaptive coping strategies of synergizing, interfacing, compromising, and system maintenance. Synergizing refers to the family coming together as a coherent unit to accomplish a shared lifestyle. Interfacing refers to the interfacing of family needs and community resources. When a family uses the coping strategy of compromising, they accept their circumstance including what they can and cannot change. The last coping strategy for a family to successfully consolidate is system maintenance, which refers to the ability of families to integrate, and offer morale and esteem. McCubbin and Patterson further state that families do not always progress through the FAAR model in a linear fashion, and it may be possible for families to remain fixed at one phase.

Similar to the FAAR model, other researchers have suggested that a family's ability to adapt to their child's disability is correlated with family structure, cohesion, and reciprocal interpersonal relations (Mahoney

et al., 1992; Dyson, 1997). Whether a family unit will be able to maintain structure, remain cohesive, and engage in reciprocal interpersonal relations while enduring the stresses brought upon by raising a child with a disability is dependent on numerous factors. In their review of the literature, Yau and Li-Tsang (1999) found a set of parental characteristics in families that adapted well to the presence of a disability. Such characteristics included a high level of education, a well-adjusted personality, good problem solving skills, and positive and realistic expectations of the child.

Aside from parental characteristics, the type and severity of disability a child has may also impede parents' ability to adjust (Kazak, 1989). Diagnostic ambiguity or ambiguity over the etiology of the disorder has also been studied as a factor contributing to parents' inability to adapt. Research has shown that ambiguity is related to lower levels of family harmony (Perry et al., 2005) and greater levels of stress (Norton & Drew, 1994). Furthermore, Frey, Fewell, and Vadasy (1989) found that parents experienced a greater level of difficulty adjusting to their child's disability if severe communication impairment was present. Taking into account the latter factors, it is important to study the effects

that autism poses on a family, given that it is a pervasive developmental disorder with an unknown etiology that affects a child's ability to communicate verbally and non verbally. In addition, the diagnostic criteria for autism states that not only do children display a lack of spoken language, but engage in inappropriate repetitive and restricted behaviors, lack the ability to engage in social or emotional reciprocity, and may exhibit aggressive behaviors towards themselves and others (American Psychiatric Association, Diagnostic and Statistical Manual of Mental Disorders: Fourth Edition - Text Revision, 2000). Due to the ambiguity, severity, and duration of autism, it would not be unusual for parents to experience elevated levels of stress when raising a child diagnosed with this disorder (Briston & Schopler, 1984).

Research has in fact shown that parents of children with autism experience higher levels of stress than parents of typically developing children, as well as parents of children with Down syndrome, parents of children with mental retardation, parents of children with cystic fibrosis, and parents of children with other developmental disabilities (Bouma & Schweitzer, 1990; Donovan, 1988; Fisman, Wolf, & Noh, 1989; Holroyd & McArthur, 1976; Konstantareas, 1991; McKinney & Peterson,

1987). In addition, Weiss (2002) found that when compared to mothers of children with mental retardation and mothers of typically developing children, mothers of children with autism reported being more distressed across all measures studied: depressive symptoms, anxiety and somatic symptoms, and parental burnout.

Research also indicates that parents of children with autism experience problems in other areas as well. Gray (1994) found that while some parents of children with autism had to decrease the number of hours they worked as well as limit their choices in career options, most parents had to relinquish their occupation due to the demands of caring for their child with autism. Parents of children with autism are also affected by the limited number of hours they sleep each night. One study indicated that parents who had a child with autism might function daily on only three to four hours of sleep (Norton & Drew, 1994). The findings reported by Gray, as well as those of Norton and Drew may contribute to the elevated levels of stress reported by parents of children with autism. Other factors that have been reported to contribute to this elevated stress are limited family opportunities and the dependency of the child (Koegel et al., 1992). In addition, Gray and Holden (1992) found that the stress

experienced by parents may also be related to the aggressive and repetitive behaviors exhibited by children with autism such as self-injurious, tantrums, and obsessive-compulsive behaviors. This is consistent with the finding that child maladaptive behaviors are related to greater levels of parental distress (Baker et al., 2002; Gray, 2002; Hastings & Johnson, 2001). Furthermore, Gray and Holden state that when a disability is not evidently identifiable through physical appearance, parents may experience more stress. Such may be the case with autism.

Inevitably, the level of stress experienced by parents caring for a child with autism is elevated. Research has suggested that the difference in stress between parents of children with autism and parents of children with other disabilities may be affected by moderating variables such as coping strategies, marital relationships, and family style (Perry, 2005). Thus, it is vital to understand how parents cope with the presence of autism in order to fully understand the interplay of factors contributing to family functioning.

Research on parental coping styles is extensive, with a plethora of studies focusing on parental coping styles with children who have disabilities. However, existing

research has produced mixed results. Margalit and Ankonina (1991) and Margalit, Raviv, and Ankonina (1992), found that parents who had children with disabilities tended to employ an avoidant style of coping involving strategies such as minimizing, escaping, or denying the stressful situation. Margalit and colleagues further found that parents of children who displayed more disruptive behavior such as those in emotional or behavioral disorders were more likely to employ an avoidant style of coping versus parents of children with learning disabilities and mental retardation. In contrast, Judge (1998) concluded that over half of the parents of children with developmental disabilities employed problem-focused strategies such as seeking support and actively solving the problem. Likewise, in a study that focused on children with physical disabilities, it was found that parents employed coping strategies that attributed cause and meaning to the child's disability as well viewing themselves as in control of the situation (Snell & Rosen, 1997). Cheng and Tang (1995) focused on parents of children with Down syndrome and found that in order to escape the rejection and public stares of strangers an avoidant style of coping was reported most frequently. However, in this same study, it was found that parents also reported using self-reliant

coping strategies, which involved taking an active stance through seeking information or attending workshops. Despite the varied results reported in the literature, research has shown that active problem solving coping strategies such as seeking information, and utilizing professional services are associated with adjustment, whereas the use of avoidant coping strategies such as wishful thinking or blaming oneself are associated with greater degrees of distress in parents of children with disabilities (Frey, Greenberg, & Fewell, 1989).

The coping styles employed by parents of children with autism have not been studied as extensively as other disabilities. In addition, the limited number of studies that have looked at autism and parental coping have produced contradictory results. One study found that parents of children with autism employed a combination of both positive and negative coping styles, such as seeking treatment services while concurrently withdrawing from others socially (Gray, 1994). Using the same sample, Gray followed up with these same parents ten years later and found that the most significant change in coping strategies indicated that parents were no longer seeking treatment services (Gray, 2002). Similarly, another study showed that parents of children with autism tended to use

coping behaviors that led to distancing themselves from stressful situations (Sivberg, 2002). In contrast, a more recent study found that strong spousal support, high self-esteem, and remaining optimistic were to some degree helpful coping strategies for parents who served as the primary care provider for the child with autism (Higgins, Bailey, & Pierce, 2005). Another study found that acquiring social support and reframing the situation in a more positive form were the two most frequent coping strategies reported by parents of children with autism (Luther, Canham, & Cureton, 2005). Other research has found that parents of children with autism use a variety of coping methods such as active avoidance coping, problem-focused coping, positive coping (positive reframing of the situation), and religious/denial coping (Hastings, Kovshoff, Brown, et al., 2005).

Although the literature on parental coping in children with autism is limited some research suggests that parents may not be coping adaptively (Gray, 2002; Sivberg, 2002). As a result of the aforementioned findings, researchers have begun to look at family functioning in families of children with autism. Hanline (1991) states that disruptions are likely to occur in the family life cycle when there is a member of the family

with a disability. Thus, it is imperative to examine the effects at the family level. Due to the distinct experiences that parents may encounter when caring for a child with a disability, particularly autism, it is of critical importance to examine the effects on family functioning from a family systems and ecological standpoint (Bronfrenbrenner, 1986; Quittner & DiGirolamo, 1998). In particular, because having a child with a disability can contribute to hardships for parents and the family, it is important to employ a family-centered approach when studying the impact of children with disabilities on the family unit and each member within that unit (Sontag, 1996; Sweeney & Hoffman, 2004). Tunali and Power (1993) assert that a family systems approach is most appropriate when studying stress and coping in families of children with developmental disabilities. Furthermore, the authors specified that in order to help families deal with the impact of a child with autism, changes and adjustments must be made at both the individual level and the family level. In addition, Keller and Honig (2004) concluded that when providing services to families of children with disabilities, the entire family system must be taken into consideration.

The literature on family functioning in children with disabilities suggest that adaptive coping by parents is related to a greater level of family functioning in families of children with disabilities (Dyson, 1997; Failla & Jones, 1991). Similarly, Keller and Honig (2004) concluded that a positive coping style in parents who had children with disabilities predicted a satisfactory family environment and minimized stress. Failla and Jones looked at mothers of children with developmental disabilities and found that a high satisfaction with family functioning was related to the use of coping strategies that involved maintaining family integration. Furthermore, results indicated that mothers who had lower satisfaction with family functioning experienced greater levels of family stress. In a separate study that focused on parents of children with several types of disabilities, results showed that parents experienced lower levels of stress when the family environment emphasized individual personal growth and organized routines (Dyson, 1991). In their study, Margalit and colleagues (1992) found that because parents of children with disabilities were not able to foster growth, or provide support to other family members', parents reported feeling that their families were characterized by less cohesion. Furthermore, in a

separate study it was concluded that parents who employed an avoidance style of coping reported a family environment characterized by less support and a decrease in the ability to provide personal growth when compared to parents who did not adopt that style of coping (Margalit & Ankonina, 1991). In addition, Judge (1998) found that the use of a negative style of coping such as self-blaming or wishful thinking had a negative impact on families with regard to mastery or competence.

Despite the ample number of studies on family functioning in children with disabilities, there are a limited number of studies that have been conducted on coping in parents of children with autism. To date, only four studies have focused on family functioning in families of children with autism (Higgins, Bailey, & Pearce, 2005; Perry, Harris, & Minnes, 2005; Rodrigue, Morgan, & Geffken, 1990; Sivberg, 2002). Rodrigue and colleagues compared the family environments of mothers of children with autism to mothers of children with Down syndrome and mothers of typically developing children, and concluded that mothers of children with autism experienced higher levels of cohesion but lower levels of family adaptability in comparison to the other two groups. However, more recent research has failed to support that

finding. In Sivberg's study, a comparison between families of children with autism and those of a control group was carried out. Among both groups it was found that greater levels of strain on the family were a result of lower levels of parental coping. Furthermore, results indicated that in families of children with autism the level of family strain was greater than that of the control group. The findings, thus, suggest that parents of children autism may not be coping as adaptively as one would hope. Perry and colleagues used the *Family Environment Scale* (Moos, & Moos, 1981) to examine and compare the family environments of parents of children with different developmental disabilities (Down syndrome, Fragile X syndrome, Rett's syndrome, autism, and developmental disability unknown etiology) to the families on which the FES was normed, which consisted of 1,215 typical families and 500 distressed families. The researchers found that there were no significant differences in family functioning in families who had children with developmental disabilities when compared to the typical or distressed families on which the FES scale was normed. In addition, results indicated no resemblance in the family environments of families who had children with developmental disabilities to that of the distressed

families. Furthermore, the researchers concluded no significant differences in family environment as a result of type of developmental disability, severity, or child age.

One final study that has focused on autism and family functioning, looked at the relationship among characteristics of autism, family functioning, and coping in primary caregivers and compared this to normative groups (Higgins et al.). Results indicated that primary caregivers of children with autism reported less marital happiness, less cohesion, and lower family adaptability than evidenced by normative groups. In addition, it was found that coping strategies were not significant predictors of marital or family adjustment. However, the researchers did find that almost half of the families reported physical, emotional, financial, or marital distress. These families also characterized their environments as lacking warmth, connection, and a degree of flexibility. In addition to the latter finding, 25% of the participants in this study reported that having a child with autism had a negative effect on their family life.

The purpose of the present study was to build on the existing literature by examining the effects of parental

coping on family functioning in families of children with autism. Previous studies that have looked at coping and family functioning in children with autism contained methodological concerns that are worth noting. Participants in the study conducted by Sivberg (2002) were derived from a center for autism, thus, all children had an independent diagnosis. However, the author did not measure children's severity of autism. Therefore, the relationship between autism severity and family adjustment could not be examined. This study also contained a small sample size of 37 parent dyads of children with autism spectrum disorder and 37 parent dyads of typically developing children. Of the 37 children with autism spectrum disorder nine had Asperger's syndrome, the remainder of the children (N = 28) met criteria for autism. Another methodological concern was that this study was conducted in Sweden, thus, results may not generalize to other populations. In addition, the scale used for family functioning, the Family Relations Scale, a Swedish instrument is not widely recognized.

The study conducted by Perry and colleagues (2005) included a large sample size (205 parents), however, the authors did not focus solely on autism. Instead, they studied families of children with one of five different

types of developmental disabilities. Furthermore, researchers did not use an independent scale to measure coping, relying on a subscale on the Family Environment Scale to measure coping resources. Although the authors in this study looked at severity across developmental disabilities, information on diagnoses and level of severity were both based on parent report. This study concluded that there were no differences in families of children with disabilities with regard to type of disability, severity, or age, which contradicts other research suggesting that the type and severity of disability may affect parents' ability to adjust (Kazak, 1989). Such contradiction may be explained by the fact that the information on disability and level of severity in the Perry and colleagues study was obtained through parental report rather than a measure. The last study, conducted by Higgins and colleagues (2005), which is the most pertinent to the present study, also did not assess the severity level of children with autism, which has been shown to be an important variable to consider when examining parental or family adjustment (Kazak, 1989). In addition, this study had a return response rate of 40% and the sample size for this study was only 53. Although the measures used for family functioning and coping in this

study are well known in the literature the study was conducted using an Australian population, therefore results may not generalize to other populations.

Methodological improvements of the present study included a larger and more diverse sample size than in prior studies, as well as the use of independent measures for coping and family functioning. Another methodological strength of the present study was the use of an independent diagnosis of autism as well as a measure which indicates the severity of autism, which previous researchers has failed to provide. It was imperative to include a measure that indicates the level of autism as it permits and supports the statistical examination of the variables of interest in the present study. Thus, it enabled the researchers to examine the affect of autism severity on family functioning.

The purpose of the present study was to explore the relationship between level of autism severity and family processes. In addition, the relationship of coping between autism and family processes was also explored as a mediational variable. The following hypotheses were examined:

Hypothesis #1: Based on the stress and coping literature (Higgins et al., 2005; Keller &

Honig, 2004; Sivberg, 2002; Margalit et al., 1992; Failla & Jones, 1991) it was hypothesized that level of autism would negatively correlate with family cohesion and positively correlate with family conflict.

Hypothesis #2: The relationship between each of the coping styles and the family environment variables (cohesion and conflict) was explored. It was hypothesized that positive styles of coping (dealing with the problem, optimism, and sharing) would be positively correlated with family cohesion and negatively correlated with family conflict, whereas a negative style of coping (nonproductive coping) would be negatively correlated with family cohesion and positively correlated with family conflict.

Hypothesis #3: It was hypothesized that coping would mediate the association between autism severity and family functioning. Eight separate mediational hypotheses were tested evaluating every combination of the single predictor (autism severity), two criteria (family cohesion and conflict) and four mediators (dealing with

the problem, optimism, sharing, and nonproductive coping).

Furthermore, exploratory analyses were conducted to examine the relationship between level of autism severity and each of the four coping styles (dealing with the problem, optimism, sharing, and nonproductive coping). Since no previous research has looked at this relationship a hypothesis predicting a correlation was not formulated.

CHAPTER TWO

METHOD

Participants

Participants for the present study were mothers and their children with autism enrolled in the University Center for Developmental Disabilities (UCDD), located on campus, at California State University, San Bernardino. UCDD is an intervention/educational/research program based on the ecological/context model suggested by Sweeney and Hoffman (2004). UCDD serves parents and their children with developmental disabilities, predominantly autism (80%). Parents and consumer children attend weekly two and one half hour sessions during which children receive one-to-one behavioral treatment while parents attend a support group. The local California State Regional Center refers and provides funding for qualified consumer children and/or adolescents with developmental disabilities and their families who receive treatment services at the center (California Department of Developmental Disabilities, 2002).

Parents who completed the Gilliam Autism Rating Scale - Second Edition (GARS-2), the Coping Scale for Adults (CSA), and the Family Environment Scale (FES) were

eligible for participation in the present study. Participants were comprised of mothers attending the treatment program at the time of data collection. A total of 146 mothers volunteered to participate in the research program. All participants had a child with an independent diagnosis of autism (*DSM-IV*-TR, 2000). Demographics reported by mothers were as follows: African American/Black, *n* = 18 (12.3%); Asian/Pacific Islander, *n* = 5 (3.4%); Hispanic/Latino, *n* = 42 (28.8%); White/Caucasian, *n* = 59 (40.4%); Mixed Ethnicity or other, *n* = 12 (8.3%); unknown, *n* = 9 (6.2%). Parent education levels were reported as: 14 (9.6%) No High school or some High School; 22 (15.1%) were High School Graduates; 66 (45.2%) had some College and/or AA Degree; 22(15.1%) reported Bachelor's Degree; and 14 (9.6%) had Post Graduate Degrees or study. Reported annual family incomes were: 23 (15.8%) less than $24,000; 47 (32.2%) between $24,000 and $59,999; 56 (38.4%) greater than $60,000. In addition, 103 (70.5%) of the mothers reported being married; 13 (8.9%) reported that they were single; 21 (14.4%) divorced or separated, and 1 (.7%) widowed. Mothers each had a child with an independent diagnosis of autism (*DSM-IV*-TR, 2000) enrolled at UCDD. Children's gender were reported as follows 79.5% male and 20.5%

female, with child's age ranging from 3 - 19 years (M = 8.78, SD = 3.133).

The UCDD research program was reviewed and approved by the Institutional Review Board on campus. Participants were treated in accordance with the "Ethical Principles of Psychologist and Code of Conduct" (American Psychological Association, 1992).

Measures

Coping Scale for Adults

The *Coping Scale for Adults* (*CSA*; Frydenberg & Lewis, 1997) long form was used to assess parental coping styles. Consisting of 82 items in total the *CSA* is comprised of four coping style subscales: *Dealing with the Problem, Remaining Optimistic, Sharing, and Nonproductive Coping. Dealing with the Problem* subscale measures the extent to which individuals focus on solving the problem, work hard, improve on existing relationships, seek relaxing diversions, engage in physical recreational activities, protect oneself, and use humor (28 items, e.g., "Assess the situation"). *Remaining Optimistic* subscale consists of items measuring seeking spiritual support, focusing on the positive, and seeking relaxing diversions (15 items, e.g., "Try to have a cheerful outlook on life"). The *Sharing*

subscale measures the extent to which individuals seek social support, engage in social action, and seek professional help (12 items, e.g., "Join with people who have the same concern"). The *Nonproductive Coping* subscale consists of items measuring the extent to which individuals worry, engage in wishful thinking, engage in tension reduction, ignore the problem, self-blame, keep to self, and not cope (26 items, e.g., "Put the problem out of my mind"). Responses to each question range from 1 (not used at all) to 5 (used a great deal). The CSA has demonstrated good internal consistency. Crobach's alpha for each of the four coping style subscales are as follows: dealing with the problem .88, sharing .84, optimism .77, and nonproductive coping .91 (Frydenberg & Lewis). To compute scores for each of the subscales, scores in each of the items measured within a subscale were summed and divided by the total number of items measured being asked, for example, the optimism coping subscale measured coping in three different areas: seeking spiritual support, focusing on the positive, and seeking relaxing diversions. Scores for the optimism subscale were added and divided by three. The scores summed together from each of the subscales yield a total score that could range from 5 (low use of that coping style) to 105 (high

use of that coping style). Higher scores on each of the subscales were indicative of high use of that particular coping style.

Family Environment Scale

The *Family Environment Scale* (*FES;* Moos & Moos, 1981) was used to assess the degree/amount of family cohesiveness and family conflict. The FES is a 90-item true or false scale comprised of 10 subscales assessing three dimensions of family systems: Relationship, which measures the degree of *cohesion, expressiveness,* and *conflict* in the family; Personal Growth, which measures the degree of emphasis on *independence, achievement orientation, intellectual/cultural orientation, active/recreational orientation,* and *moral/religious orientation;* and System maintenance which measures *organization,* and *control*. Internal consistencies for the 10 subscales range from .61 to .87 and test-retest reliability range from .68 to .86, both which are within acceptable range (Moos & Moos, 1981). Higher scores imply greater family emphasis within that subscale, lower scores imply less family emphasis within that subscale. For the purposes of the present study only the *cohesion* subscale, which measures the degree of commitment, help, and support family members provide for one another (e.g., "Family

members really help and support one another") and the *conflict* subscale, which measures the degree of openly expressed anger and conflict among family members (e.g., "Family members sometimes get so angry they throw things") of the relationship dimension were used.

Gilliam Autism Rating Scale - Second Edition

The *Gilliam Autism Rating Scale - Second Edition* (*GARS*-2; Gilliam, 2005), derived from the diagnostic criteria in the *DSM-IV*-TR (2000) and from the Autism Society of Americas' (2003), is a professional and parent report instrument that evaluates autism symptomology. It was used to assess children on each of three domains of autism (Stereotyped Behavior, Communication, and Social Interaction). Combined scores on these subscales yields an Autism Index (AI) score (with a Mean of 100 and *SD* of 15); which was used in the present study to indicate the degree of severity of the disorder. AI provides a total score assessing the probability of autism with higher scores indicating a greater degree of severity. The manual (Gilliam, 2005) reports that standard scores were obtained from a normative sample of children and young adults diagnosed with autism (N = 1,107) and that 90% obtained AI scores $\geq$ 85; adequate validity and reliability were also reported for each of the test domains and the AI. The

previous version of the GARS (Gilliam, 1995) was recommended for use in the diagnosis of autism (Filipek, et al., 2000; NCR 2001). The GARS-2, used here, was revised to reflect the most current definitions of autism (APA, 2000).

Procedures

Initial behavioral information regarding children was collected from the state agency during the referral process, with additional consumer and family information obtained from parents and existing agency records. Parents and consumers were assessed in a two-part process, with specially trained research assistants or center staff completing the first part of the assessment (including the GARS-2) at the parent's home. Parents were then given an intake packet containing an overview of the programs of treatment, evaluation, and research. Upon completion of the parent consultation and consumer observation, the informed consent was obtained from the parent. For the second part of this process mothers met individually with a research assistant to complete the CSA, the FES, and other measures that are part of the ongoing research and evaluation program. Completion of the research packet lasted approximately two hours. All assessment measures

were read aloud to the parents by a research assistant. In order to ensure confidentiality and anonymity a display card was placed between the researcher and the parent, which served as a barrier and an aid for parents in responding to each question. In addition, upon completion, answer sheets were sealed in a plain envelope and identified with a predetermined code number.

Statistical Analysis

Pearson-product moment correlation coefficients were calculated and tested for their significance for hypotheses one and two: the predictor variable AI and each of the criterion family environment variables (cohesion and conflict); and each of the parental coping style variables (dealing with the problem, optimism, sharing, and nonproductive coping) and each of the criterion family environment variables (cohesion, and conflict). Pearson-product moment correlations were also calculated and tested for the exploratory analysis: AI and each of the parental coping style variables (dealing with the problem, optimism, sharing, and nonproductive coping). To test the significance of hypothesis three, coping as a mediational variable between AI, and conflict and cohesion, a test of the intervening variable effect

proposed by Mackinnon, Lockwood, and Hoffman (1998) was applied. The product of α (the raw regressions coefficient for the primary predictor, autism severity) and β (the raw regression coefficient for the mediator, nonproductive coping) as a predictor of the primary criterion (cohesion or conflict) after adjustment for the effect of the primary predictor (autism severity) were tested for significance using the z' distribution. The null assumes that $\alpha\beta = 0$ (Mackinnon et al., 2002). A significance level of $p = .05$ was implemented to test the significance of the obtained results.

CHAPTER THREE

RESULTS

Descriptive statistics for the variables of interest are presented in table 1.

Table 1. Descriptive Statistics for Variables of Interest

	Mean	Std. Deviation	Min Value	Max Value
CSA				
Dealing with the Problem	94.49	14.16	55	128
Optimism	50.12	7.64	29	71
Sharing	23.69	10.98	-5	51
Nonproductive Coping	66.52	15.36	32	108
FES				
Cohesion	7.31	1.72	2	9
Conflict	2.64	1.98	0	8
GARS				
Autism Index	94.82	17.25	61	139

The normality of each of the variables presented in Table 1 was checked. The only violations of normality were on the family environment variables, with cohesion being negatively skewed and conflict being positively skewed. In addition to screening for the normality, the researchers also looked for outliers on each of the measured variables by using the three and a half times the standard deviation method. Calculations indicated there were no outliers on any of the measured variables. Furthermore, scatter plots

were observed to evaluate linearity and homoscedasticity. Graphs illustrated a linear fit on all measured variables, however, there was some heteroscedasticity with a propensity of large negative residuals.

Results for the first hypothesis, the relationship between level of autism severity and family cohesion and conflict, were partially supported. The findings indicated that children's severity of autism (AI scores) was unrelated to FES Conflict scores ($r = .12$, $p = .153$) but was negatively correlated with FES Cohesiveness ($r = -.23$, $p = .005$). The second hypothesis of this study was that positive styles of coping would be positively correlated with family cohesion and negatively correlated with family conflict, and negative styles of coping would be negatively correlated with family cohesion and positively correlated with family conflict. The correlations between each of the FES measures of family functioning, cohesion and conflict, and each of the four coping styles assessed are listed in Table 2. As indicated, the three positive coping styles were each positively correlated with family cohesion and negatively correlated with family conflict. Also as predicted, nonproductive coping was negatively related to family cohesion and positively related with family conflict.

Table 2. Pearson Correlations between Parents' Coping Style, and Family Cohesiveness and Conflict

	Coping Style			
FES	Dealing	Optimism	Sharing	Nonproductive
Cohesion	.38 ($p < .001$)	.34 ($p = .001$)	.27 ($p < .001$)	-.39 ($p < .001$)
Conflict	-.32 ($p < .001$)	-.29 ($p < .001$)	-.29 ($p < .001$)	.36 ($p < .001$)

Based on the obtained correlations, two separate regression analyses were conducted to examine the contributions of AI and coping styles to FES cohesion and FES conflict (treated as the dependent variable in each analysis). In the first analysis, AI was entered on Step 1 and accounted for approximately 5% of the variance in predicting FES cohesion, ($R^2 = .05$, $F (1, 144) = 7.90$, $p = .006$). On Step 2 the four coping styles (entered together) predicted an additional 21% of the variance for cohesion, (R^2 change $= .21$, $F (4, 140) = 9.94$, $p < .001$). In this latter Step (Model 2) of the regression, Optimism and Sharing did not affect the relationship evidenced between AI and cohesion. However, both Dealing with the Problem (Beta = .20, $t = 2.02$, $p = .045$) and Nonproductive Coping (Beta = -.25, $t = -3.04$, $p = .003$) and the impact of AI marginal (Beta = -.16, $t = -2.07$, $p = .04$) were significant (see table 3 for complete regression analyses)

Table 3. Hierarchical Multiple Regression Analyses for Family Cohesion

Variables	R	R^2	Raw β	Std. β	t value	p Value
Step 1						
AI	0.228	0.052	0.008	-0.228	-2.811	0.006
Step 2						
AI	0.512	0.262	-0.015	-0.115	-2.069	0.04
Dealing w/ the Problem			0.025	0.202	2.02	0.045
Optimism			0.013	0.058	0.629	0.53
Sharing			0.018	0.113	1.253	0.212
Nonproductive Coping			-0.027	-0.245	-3.035	0.003

In the second analysis we examined the contributions of AI and coping styles to FES conflict (treated as the dependent variable). AI, entered on Step 1 accounted for 1% of the variance in predicting FES conflict, (R^2 = .01, F (1, 144) = 2.03, p = .156). On Step 2 the four coping styles (entered together) predicted an additional 19% of the variance for conflict, (R^2 change = .19, F (4, 140) = 8.18, p < .001). The three positive coping styles examined in this latter Step (Model 2) of the regression did not affect the relationship evidenced between AI and conflict. Only Nonproductive Coping was significant (Beta = .27, t = 3.22, p = .002) (refer to table 4 for complete regression analyses).

Table 4. Hierarchical Multiple Regression Analyses for Family Conflict

Variables	R	R^2	Raw β	Std. β	t value	p Value
Step 1						
AI	0.118	0.014	0.014	0.118	1.426	0.156
Step 2						
AI	0.448	0.2	0.005	0.042	0.541	0.589
Dealing w/ the Problem			-0.014	-0.013	-0.988	0.325
Optimism			-0.041	-0.16	-1.67	0.097
Sharing			-0.012	-0.067	-0.719	0.473
Nonproductive Coping			0.035	0.271	3.223	0.002

Results for the exploratory analysis between level of autism severity and each of the four coping styles indicated that AI was unrelated to any of the three positive coping styles measured (Dealing with the problem, Optimism, and Sharing). However, AI was found to be correlated with nonproductive coping scores (r = .24, p = .004).

In order to test the mediational relationship of coping style on autism severity and family cohesion and conflict, the z′ distribution proposed by Mackinnon and colleagues (2002) was applied. The following formula was used to calculate z - prime: $z' = \frac{ab}{\sqrt{as_b + bs_a}}$. Since AI was found to be unrelated to any of the three positive coping

styles in the exploratory analysis, only the mediational variable of nonproductive coping was used to examine the relationship between autism and family cohesion and conflict. The raw coefficients are presented first followed by the standard coefficient scores. Both were used to calculate the mediational effect of nonproductive coping between AI and cohesion and conflict.

In the standard coefficient models, AI and nonproductive coping had a significant small to medium effect size (r = .24, p = .01). The bivariate relationship between nonproductive coping and family cohesion was also significant (r = -.39, p = .001) with a medium to large effect size. As shown in Figure 1, results indicated a significant zero order correlation between AI and family cohesion (r = -.23, p = .01) when accounted for by nonproductive coping the relationship was not significant dropping a magnitude of .09 (r = -.14, p = .05), accounting for only two percent of the variance between AI and family cohesion.

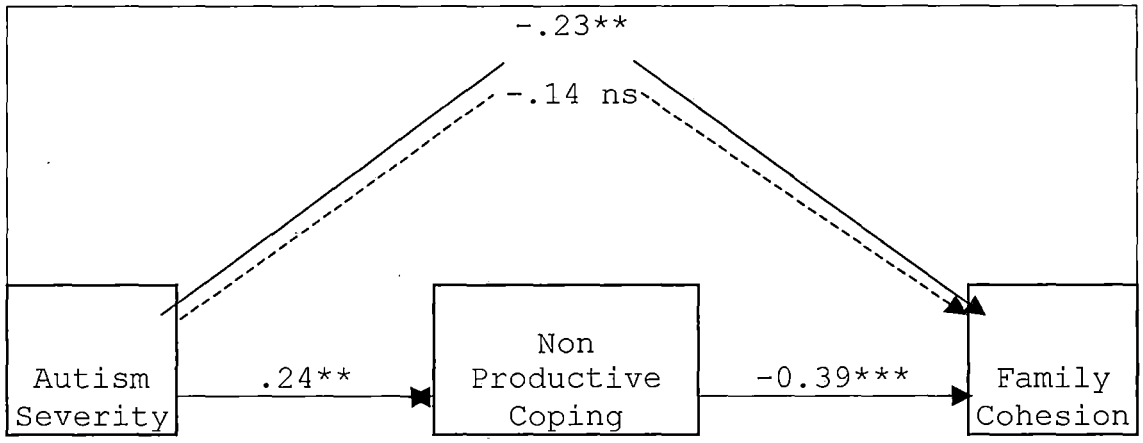

Figure 1. Standard Coefficients Model of Non Productive Coping on Autism Severity and Family Cohesion

Results for the criterion variable, conflict illustrated in Figure 2 were also non significant. The findings indicated the bivariate relationship between nonproductive coping and family conflict to be significant (r = .36, p = .01). However, the zero order correlation between AI and family conflict was not significant (r = .12, p = .05), and when accounted for by nonproductive coping the relationship dropped a magnitude of .08 (r = .04, p = .05).

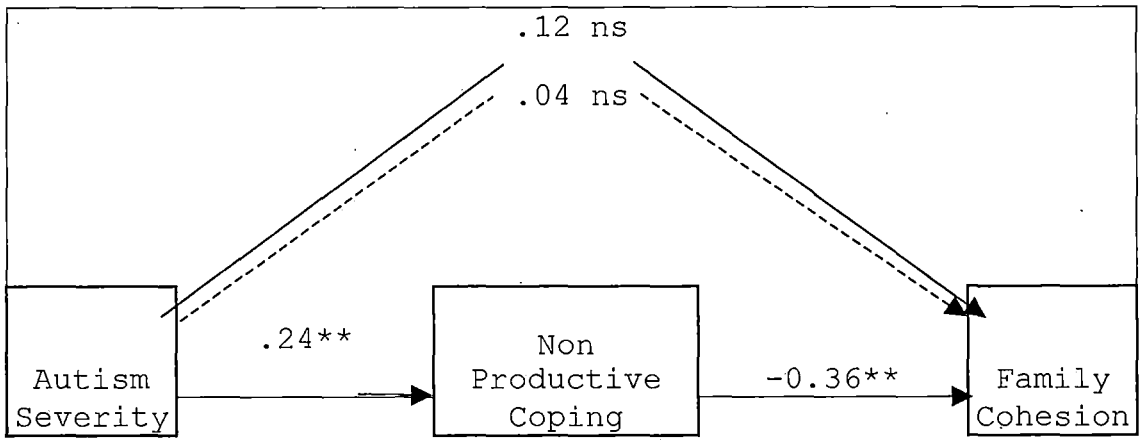

Figure 2. Standard Coefficients Model for Non Productive Coping on Autism Severity and Family Conflict

Both z′ prime for cohesion model and the conflict model were statistically significant, cohesion ($z' = -2.43$, $p = .015$), conflict ($z' = 2.44$, $p = .015$). The total effect for the cohesion model was -.227 (mediation effect = -.084; direct effect = -.144) and for the conflict model the total effect was .124 (mediation effect = .088; direct effect = .036). Thus, our hypothesis of nonproductive coping mediating the relationship between AI and family functioning (cohesion and conflict) was supported.

CHAPTER FOUR

DISCUSSION

The present study investigated the effects of having a child with autism on parental coping and family functioning. It was hypothesized that autistic severity would be negatively correlated with family cohesion and positively correlated with family conflict. Our findings indicated partial support for this hypothesis. Results suggested a negative correlation between severity of autism and family cohesion. Thus, as the level of autism severity increases the degree of family cohesion decreases. This finding parallels the results reported by Mahoney and colleagues (1992) who found that regardless of disability, families consistently reported being more distressed when the child's disability was severe in nature. Research however, has also found that independent of autistic severity parents of children with autism report low levels of family adaptability and low levels of family cohesion (Higgins et al., 2005). This finding is also in line with the results reported by Perry and colleagues (2005) who found that despite severity, parents of children with autism reported lower levels of family harmony than parents of children with other developmental

disabilities. Although severity of autism was not related to family conflict, the finding from the present study and those from previous studies imply that families of children with autism may lack a degree of commitment, help, and support family members provide to one another, particularly when the level of autism severity is high.

As anticipated, results for our second hypothesis indicated that mothers' use of positive styles of coping was positively related to family cohesion and negatively related to family conflict. While mothers' use of a negative style of coping or nonproductive coping was negatively related to family cohesion and positively related to family conflict. This finding concurs with previous research highlighting that adaptive or positive coping is associated with higher levels of family functioning (Failla, & Jones, 1991; Keller, & Honig, 2004; Sivberg 2002). In order to investigate the contributions of level of autism severity and coping styles to FES cohesion two separate analyses were conducted. These analyses revealed that mothers' use of positive coping (dealing with the problem, remaining optimistic and sharing) did not contribute to the relationship between autism severity and family cohesion. A potential explanation for this finding could be attributed to the

fact parents' first need to cope with the ambiguity involved in the diagnosis of autism. Tunali and Power (1992) specify that parents rearing a child with autism must learn to cope with ambiguity over the etiology of the disorder, the prognosis, expectations regarding capabilities and potential of the child, and the availability of services. It could be argued that regardless of how effectively a parent copes, the presence of ambiguity and learning how to tolerate this ambiguity impedes a family's ability to remain cohesive. This is consistent with the findings reported by Perry and colleagues (2005) who found that diagnostic ambiguity was associated with lower levels of family harmony. Another potential explanation for this finding may be that as level of autism severity increases, a parent's ability to provide help, support, and commitment to family members diminishes as time and energy are usually directed toward the child with autism.

The analyses carried out further revealed that nonproductive coping adversely affects family cohesion beyond severity and is positively related to family conflict. Thus, parents' use of this form of coping, which entails worrying, engaging in tension reduction, ignoring the problem, self-blaming, keeping to self, and not coping

undermines family functioning. This finding is supported by the literature, which indicates that nonproductive or lower levels of coping lead to strain on the family system (Margalit et al., 1992; Rodrigue et al., 1990; Sivberg, 2002). However, there has been one study indicating that coping strategies did not predict family nor marital adjustment (Higgins et al., 2005).

Perhaps the discrepancy in the literature could be attributed to the fact over half of this study's sample was comprised of children diagnosed as high functioning autism (Higgins). In addition, the scale used to measure coping strategies consisted of only three factors: self-esteem, optimism, and spousal support. It could be argued that these three factors are too broad and do not measure specific and concrete coping strategies. Although mixed results have been reported in the literature, research has consistently confirmed that a negative style of coping such as distancing oneself leads to lower family adjustment (Judge, 1998; Margalit et al., 1991, 1992; Sivberg, 2002). Previous literature has further noted that parents of children with autism and other disabilities have a propensity to employ a negative style of coping using strategies such as avoidance or distancing oneself, and engaging in self-blame (Judge, 1998; Margalit et al.,

1992; Rodrigue et al., 1990; Sivberg, 2002). In conjunction with the aforementioned findings Hastings and colleagues (2005), concluded that a negative style of coping such as active avoidance coping is an ineffective method when attempting to cope with the demands of raising a child with autism. Therefore, the findings from the present study and those of previous studies suggest that families of children with autism may benefit from services that offer coping skills training.

The present study also sought to explore the relationship between level of autism severity and each of the four coping styles. Since no previous research has looked at this relationship no hypotheses were derived. The exploratory analyses revealed that the level of autism severity was unrelated to any of the three positive styles of coping. A potential explanation for this finding could be the ambiguity associated with the diagnosis of autism in terms of etiology and prognosis. Another potential explanation could be that perhaps the mothers' in the present study felt that the demands of raising a child with severe autism superseded their ability to use positive forms of coping. It could also be argued that regardless of how effectively mothers' were coping, the demands of raising a child with severe autism were still

going to be present, and awareness of this may have led mothers' to feel a sense of hopelessness.

However, the exploratory analysis did reveal that level of autism was related to nonproductive coping. Therefore, indicating that as severity of autism increased the use of nonproductive coping increased as well. This finding is critical as it indicates that parents of children with severe autism may be employing maladaptive coping strategies, such as those of wishful thinking, blaming one self, or avoiding the situation at hand. This finding is consistent with the aforementioned findings indicating the use of nonproductive coping in parents' of children with disabilities (Judge, 1998; Margalit et al., 1992; Rodrigue et al., 1990; Sivberg, 2002), and further highlights the importance of intervention efforts needed.

We were also interested in the mediational relationship of nonproductive coping between AI and family cohesion and conflict. It was hypothesized that nonproductive coping would mediate the association between AI and cohesion and conflict. As anticipated, results indicated that nonproductive coping was significant in mediating the relationship between AI and cohesion and conflict, which indicates that the relationship between AI and cohesion, and AI and conflict can partially explained

for by nonproductive coping. However, these analyses only revealed a small mediational relationship in both cohesion and conflict models. Perhaps there may be other main effect variables on family functioning. Literature in the area of family functioning and family adjustment has looked at other factors that may mitigate a family's ability to function or adjust. Such factors included marital status, socioeconomic status, parental characteristics, and social support (Judge, 1998; Li-Tsang, Yau, & Yuen, 2001; Trute, 1990; Yau, & Li-Tsang, 1999).

Though the present findings provide interesting directions for professionals and service care providers working with families of children with autism, limitations to this study are worthy of note. One potential limitation was that participants in the present study were all enrolled in the treatment program at UCDD. Future research should examine family functioning in parents of children with autism from a community based sample in addition to a center-based sample. Another limitation of the present study was that findings were restricted to mothers only. Because social support and a strong marital relationship have been found to be two factors that ease parents' ability to function, future studies should examine the

effects of family functioning by including the father. Inclusion of the father in research studies would appear to be beneficial given that services provided to help families of children with autism will be directed at both parents. It would also be of value for future research to focus on family coping in families of children with autism. The present study only took into account the role of parental coping in families of children with autism.

Given that the research indicates that the presence of a disability impacts the family as a unit it would be vital to examine how the family copes. This line of research would provide us with further insight on family adjustment and family functioning in families of children with autism. The present study also sought to examine the mediational relationship of nonproductive coping on AI and family functioning. Although it was found that nonproductive coping accounted for a portion of the relationship between AI and family functioning, future research should examine other main effect variables, such as marital status, socioeconomic status, parental characteristics, and social support. It may be stated that while nonproductive coping is a significant mediational variable, there may be other main effect variables such as those mentioned above that lead to a family's ability to

function at a healthier state. Lastly, when providing intervention efforts, future research should examine whether such interventions benefit parents and families of children with autism both in the short-term and in the long-term.

The findings of the present study suggest that much work is needed in providing services to families of children with autism. Results indicated that parents may not be coping as adaptively as one would hope, and that the negative style of adopted by caregivers of children with more severe autism as indicated in the present study may undermine family functioning. While the relationship between autism severity and family cohesion was not positively affected by mothers' use of positive coping, as in dealing with the problem, remaining optimistic, and sharing. It is suggested that the positive contributions of these coping styles to family cohesion is noteworthy in itself and should transmit the implementation of intervention efforts by professionals working with parents and families of children with autism to include the enhancement of coping skills. Previous research has looked at effective coping strategies of parents of children with autism (Hastings, et. al., 2005; Luther, et. al., 2005; Tunali, & Power, 2002). These studies have concluded that

social support and cognitive or positive reframing were the most successful coping strategies in parents' of children with autism. Therefore, professionals or service care providers working with families of children with autism should aim at broadening a family's social support network and educating families on cognitive appraisals and positive reframing of their circumstances.

In conclusion, the present study accentuates the need of services that families of children with autism require. For individuals working with families of children with autism, it is critical to understand how parents are coping in order to provide effective services that support family adjustment and adaptation. The present study further highlights the importance of employing a family systems or ecological approach both in research and in providing services.

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